Eating Is a Bitch

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Eating is a bitch for me. It is my strongest tie to dependency, and the one I hate the most. My Cerebral Palsy has made it impossible for me to eat independently. Although walking and talking have never been easy either, somehow I managed to achieve those developmental goals. Feeding myself is the one formative step I have never achieved. Even at the age of forty-one, I must rely on others to feed me.

As an infant, I was fed almost exclusively by my mother, since most mothers of her generation were the primary caretakers. But, because my hand control was so poor, her role had to continue well past the 'normal' age when most children begin the growth and separation process. Being fed by my mother was like using my own set of hands. There was a great familiarity between us. I grew accustomed to her method and pace; she grew accustomed to anticipating what she thought were my needs. This comfort level is something I now know I took for granted.

At my school for children with disabilities, there were very few kids who were unable to feed themselves a statistic which often surprised me. Those of us who couldn't eat independently ate lunch in the Occupational Therapy (O.T.) Department. Duffy, the occupational therapist, found the "right" gadgets and allowed us time to practice eating with our new tools. Once students learned to eat by themselves, they would graduate to the main dining room.

There were a number of good elements to eating within the O.T. Department. I got to spend lunch and some classroom time away from the rest of the school, plus I had a very positive relationship with Duffy. Retrospectively, it was like being with my mother, whom she more than likely had come to represent. I enjoyed the intimate setting, and our talks were more stimulating than they were in class or as I had imagined they would be in the lunch room.

To me, the only odd thing about my eating in the O.T. Department was the number of students who learned to feed themselves and went on to eat in the dining room. I can't begin to count the number of "graduates." Even children with Athetoid Cerebral Palsy similar to mine (or so it seemed) found the right equipment, so their stay in O.T. was short-lived. It felt so unfair that, no matter how hard I tried to feed myself, nor how many different types of equipment I used, my food still went flying and my turn to "graduate" never came.

At the time, teaching clients to eat independently was a number one priority to occupational therapists. They had a whole bag of tricks for accomplishing their mission and each therapist I met along the way tried them all - repeatedly - on me. This included many interesting gadgets. There were spoons that could be bent in many directions so that picking up food was possible by holding my hand at any comfortable angle, and a bowl that allowed food to be scooped up off its side - assuming that I was able to steadily lift my hand to the bowl to get the food. Next, there was a guard that wrapped around half the side of the plate. This was supposed to be a compromise between a flat plate and a bowl. This crossbreed sort of worked for me, but it was far from perfect.

Besides this, school was not the only place I was attempting to feed myself. I had plenty of feeding equipment at home, and for years I tried to feed myself at dinnertime. Even Uncle Austin made me an elaborate gizmo that also turned out to be unsuccessful. It damned well had become a universal obsession!

The culmination of my self-feeding odysseys occurred when I was ten or eleven. I went to a world renown rehabilitation center with almost a promise they would teach me to eat. I skeptically agreed to give it a try. I stayed there for the two weeks and left with a special ten-thousand dollar spoon! Yet, this spoon wasn't any different from all the other spoons I'd been accumulating over the

years. Once again, I had met with failure. Even the best rehabilitation center couldn't teach me to eat! As a result, after having begun eating in the O.T. Department in third grade, I found myself still there in ninth grade. It was becoming abundantly clear that I was not making as much progress as was expected, and all efforts had ultimately proven to be a waste of time.

Was eating independently worth the torture I was putting myself through? My continuous, involuntary motions were significantly increased by the physical exertion I needed to expend just to get some food into my mouth. My clothes became drenched from beads of sweat pouring down my back, making my body feel ugly. I moved, sweated, and watched with rage as my food went flying - still leaving only a few morsels in my mouth. Feeding myself even one meal took so much effort that I always felt as if I had just run a marathon.

I was also starting to feel the isolation of eating away from my peers and missing the social nuances. I no longer wanted to be separate; I wanted to be with everyone else. Perhaps I no longer needed to be in the company of Duffy, possibly an indication that I was also psychologically beginning to separate from my mother.

It soon occurred to me that it felt more natural for me to be fed by another person, even if it did leave me reliant. My self image improved, too, while being fed. I somehow felt more normal and acceptable. For some reason the idea of needing someone to assist every time I got hungry was the lesser of two evils to me. Indeed, I conserved more energy, too!!!

After all, even if I decided that the effort to meet this goal was worth it, someone else still had to cook, prepare, and cut my food, set my plate up, and of course, clean up afterwards. This procedure left me completely dependent on another person to eat, even if I could technically feed myself. Eating had become a chore and my taste for food was quickly waning.

So I finally gathered my guts and spoke up for what I believed. I can remember talking to my parents and Duffy about my frustration over trying to feed myself. I explained that I knew that hypothetically I could feed myself with the right equipment but that I wasn't the least bit interested in making the effort anymore.

I got mixed reactions from my listeners. Their responses were mostly their concerns about my future independence and how deciding not to self-feed would always leave me dependent on another person. I told them it was a conscious decision and I was willing to take this stance. I fully believe this conviction was my first act of self-determination, the first of many decisions to come! Duffy gave me her approval as well as a wise piece of advice. She said, "Never leave the house hungry; always eat first, so you don't have to worry about your next meal!" I still hear her words nearly every time I leave my house.

Taking my new declaration seriously, I graduated to the dining room, eating at the same time as my friends. Paula, one of my closest friends, offered to feed me each lunch time meal. It was a job she took on without hesitation, as a natural extension of our close friendship. Whenever our families got together outside of school she just sat on my right side, picked up my utensils, and began feeding me - an act rarely done so automatically by anyone but my mother. At last, I was with my friends and in the mainstream!

Unfortunately, my time there was short-lived, since other circumstances led to my eventual academic mainstreaming into regular high school! This transfer meant leaving the comfort of Paula's gentle hand and entering a world where I would repeatedly question my conviction that eating independently was not a practical option. I felt like I had declared my independence with eating and in the process I'd thrown myself to a pack of wolves.

Being fed was something I had come to take for granted. At home, in school, at camp and even at my friends' houses, someone had always been there to feed me. I imagined that people really didn't mind doing it. Sure, I can recall occasionally my sisters' moaning when they were asked to feed me, but I never gave their upset much credence. After all, we were sisters and I'd almost expected their reaction as a natural part of sibling rivalry. However, it had not even occurred to me that someone else would not want to feed me.

My first encounter of having to eat outside of the comfort of those locations occurred at the

time I entered regular high school. This was the first time I had to have special accommodations made for me. I was entering new territory here. I was the only obviously-disabled student with whom the school had ever dealt and neither the school, nor I, had a clue of how to meet all my unique needs, especially when it came to eating. I naively hadn't given it much thought and had presumed that people would be lining up to feed me - after all I was a nice enough person.

I went a whole week without eating lunch and sat alone in the cafeteria watching other students eat while deeply engaged in socializing. I was hungry and I was alone. I think I would have given anything to be back at my old school. Unfortunately too, I was not the type of person who physically could go without a meal because I expended too much energy to miss one! I needed the nourishment to just keep going! This was a characteristic I disliked about myself. It kept me dependent and it was to become my worst nemesis.

The high school ended up hiring a woman from town to feed me my lunch each day! She was really very nice but the whole thing seemed unnecessary. It took under fifteen minutes for me to eat and they had to pay someone to come across town just to hold a god-damn sandwich and a piece of fruit for me?! I felt diseased, and for a long time I ate separately, at my own table, in the far corner of the cafeteria. Soon I did manage to find peers to sit with but they too, for the most part, were students that no one else chose to sit with. We all seemed to be outcasts. In retrospect, my attitude was not any better than those students who refused to sit with me. I just wanted to be part of the "in crowd" because that was where my heart and head lay.

My years in regular high school were just a preview of what was to come. Eating, in particular, had a life of its own. I looked for and chose a college because of its acceptance of persons with disabilities. The newly built school was nearly barrier-free and there was a small number of students with unique needs. However even the administrators were thrown by the fact that I was unable to feed myself. At first they, and I, had no idea of how to approach my eating needs. It seemed like a new phenomenon.

To make it possible for me to get into school, a counselor managed to find a woman to room with me who agreed to feed me! What an experience that became! Her name was Glena. We had nothing in common except I felt indebted to her because she said she'd feed me for the semester. She was a sloppy person and neatness was important to me. Our apartment looked like a dump. Glena also fed me whenever and whatever she wanted to, and I passively sat back and let her call the shots. This attitude was so typical of me that often I skipped breakfast and/or dinner just because I grew tired of waiting. I felt like an indentured servant, subject to her whims and grateful for any crumbs I could get.

However instead of dealing straight on with the problem, I turned my negative feelings inward. I continued to eat only when I absolutely had to eat. If I was only slightly hungry, I skipped a meal. I drank lots of water because getting a drink was something I could do myself. It wasn't long before my resistance started to be affected and every few weeks I'd have bronchitis. Soon I found I had mononucleosis, and was so tired that I had no energy to stay awake in class, let alone complete my assignments. I returned home to recuperate and gain back the weight I had lost.

I tried to return to college with a new attitude. Eating was, unfortunately, not an optional action, it was essential! I had to develop the strategies to get help with my meals on a regular basis. It didn't take long for me to network with other students with disabilities and start learning the ropes of independence. Most students didn't necessarily need help eating; but they did need assistance getting in and out of bed, bathrooming, and/or bathing. These students were upperclassmen and had all overcome their needs simply through relying on friends to help them. This unstructured arrangement felt too casual for me and I didn't have much faith in my ability to make friends - let alone having to ask them for help eating.

I soon began dating Rick who needed assistance with nearly everything except feeding and it became almost automatic for Rick and me to eat at least one meal a day together. Usually his roommate would cook and then either Rick would feed me or one of his roommates would volunteer to help me eat. His approach to finding personal assistants was to make friends who would gladly help out. This system worked out well, mostly because the time and place were right. That college was a

very accepting place then. People with disabilities were no different than other unique populations. Receiving help was just not a big deal.

Despite the fact that eating was the one thing that kept me from being totally independent, I was able to move with my roommate, Janet, from college to an accessible apartment. Again, I was faced with the task of figuring out how I would eat while maintaining my independence. In fact, the way I got to know Janet had to do with eating. She was calmly, but continually, feeding me french fries as if I were chain-smoking them. I finally looked at her and said, "Janet, what the hell are you doing?!" She started to laugh and replied, "I've been waiting to see how long it took you to get me to stop!"

Janet, who also had a disability, was able to cook and feed herself and was, in fact, totally independent. She was technically a quadriplegic, but Gunther used to refer to her as a "super quad," since she could do everything despite the level of injury to her spine. This meant that Janet could cook and could feed me, but I knew from our experiences at college that I was not going to depend on that. I needed to eat before noon, her usual wake-up time! Instead, I had a long-time friend come in and help me eat breakfast and I put an ad in the paper and was able to get a woman to come in to feed me dinner. Janet filled in on the snacks, and was always a reliable back-up if necessary, especially when it came to french fries. That part worked out just fine.

Unfortunately, I soon found out that the eating arrangements that I had eventually developed at college were not appropriate for the rest of the world. I had to face, once again, the hard reality that feeding me was a chore, a job that no one seemed to want! Since by this time I was traveling into NYC to earn my degree at Columbia University, I now needed to arrange for eating lunch each day. I suppose I was naive, but I had assumed that I would once again make some friends, tag along for lunch, and would automatically ask someone for assistance. But, the act of asking for help just did not come easily; I felt like an imposition. Tagging along was simple enough, but asking to be fed became next to impossible! For two weeks I went hungry and by my last class I was too starved to concentrate! I soon resorted to advertising for an assistant at lunch time, but I didn't get any replies. Finally, my mother set aside two days a week to come into the city to have lunch with me, a selfless act I only now appreciate.

After a few years, Janet decided to move closer to her family and to her own accessible apartment and I remained in Bergenfield. Now I was truly living on my own except for the fact that one of my closest friends, Austin, lived downstairs and could feed me if necessary. He, too, had CP and could not really cook, but we were able to manage in cases of true hunger. Together, we decided to hire somebody to cook dinner for both of us. This situation was workable, and the fact that there was a restaurant within walking distance helped. This became our hangout; it was a local bar and Italian restaurant where everyone was laid back and went out of their way to assist us where necessary.

Eating also became an issue every time I met somebody new or attempted to go out on a date. This was particularly true if the person happened to not be disabled. It took me a long time to decide whether or not to "disclose" the fact that I needed assistance eating, and all too many dates were liquid. It was hard for me to decide what was the best approach. I was very comfortable dating people who were either disabled themselves, or who knew me well enough to know I couldn't eat by myself before the issue of dating arose. However, I didn't quite know what to do with those people whom I had just met. Should I tell them I couldn't do that? Should I ask them to feed me, or was this a way of immediately closing the door to what could eventually turn into something? I'm not sure whether it was a source of embarrassment on my part or a need to protect my own dignity. After all, I still hated that I had to be fed.

A new ray of hope did cross my path in May of 1984 when I met Michael, a guy with amazingly similar Cerebral Palsy. He used a motorized wheelchair and his speech was comparable to mine, as was his lack of hand control. In fact, our vans were even equipped in much the same way. The major difference was that Michael could feed himself simply by using his head and literally scooping the food into his mouth.

This was the first time I had seen anybody eat without using their hands at all! The fact that this method was never suggested to me still astounds me. However, even when Michael tried to teach

me how to feed myself the way he fed himself, I just couldn't do it. Sure, my mouth got to the plate; but my head shook too much and my tongue just didn't have the dexterity I needed to pick up the food. Damn, Michael made it look easy and yet, like everything else, I couldn't do it. What had appeared to be a sure answer to something I had looked for all my life was just another failure. I was pissed off and so disappointed! Yet, it did serve to amuse us, and any on-lookers, when Michael fed me by holding my silverware in his mouth!

Throughout my four years at college, I had progressed from paying someone to feed me throughout the semester, to hiring a woman from outside the college, to eating with roommates who truly convinced me they wanted to feed me. By the end of my final year at college, I believe I had found the best solution - I set up a schedule where I ate with a different friend each morning and evening and paid them to help me. This provided me the chance to spend time with different people without feeling like so much of a burden. It also gave me the opportunity to learn a lot about myself and others.

For example, David, a good friend of mine, enjoyed cooking. On one of the first occasions he fed me, he prepared hamburgers, potato, another vegetable, and a delicious salad. We sat down to eat this much-anticipated meal and David calmly asked me, "What would you like to eat first?" I clearly remember feeling dumbfounded! Whatever did he mean? I was speechless! I don't remember anyone ever having asked me that before.

I stared at my plate for what seemed like hours, occasionally looking towards David for assistance in answering his own question, but he seemed to be just calmly waiting for me to answer! I felt a rush of embarrassment flood over me, since I was rarely lost for words. It was as if David had asked the question in a different language and I couldn't translate it. I eventually said that I had no preferences and that he could arbitrarily choose the order in which he gave me my food.

With that experience, I realized that I had never made that selection. Choosing the order in which to eat food is mostly an unconscious decision for most people. They often eat while doing many other things; they talk, read, write, watch television, etc. It is an act that silently gives people a sense of self-determination. Yet in my recollection, no one had ever asked me in what order I wanted to eat my food. I honestly had given it no thought until then. I began noticing how some people choose the food randomly, while others feed me in a very orderly fashion. This pattern can be anything from a clockwise rotation to eating all of one thing at a time before moving on to the next item.

I also began noticing other things that I had never thought about before in relation to being fed. All of them have very different techniques, often mimicking the ways they feed themselves, and they are likely to give me the same portions of food on my plate as they take. What's more, people feed me at the same rate that they themselves eat. I remember comparing Josh to Nora, both friends who fed me frequently. Josh was a fast eater and fed me quickly, while Nora was just the opposite. At first I thought Nora was just scared of feeding me and that was why she was taking so long. But then I happened to have the opportunity to eat with her while I was being fed by someone else and noticed that Nora herself took forever! I reached the conclusion that I would much rather be fed by someone who eats quickly because I eat fast. Actually, I am convinced I eat fast in part because I like to get the whole thing over with and being fed slowly actually decreases my appetite.

Moreover, some people will eat with me by taking bites of food along with me, and some people will choose to feed me first and then feed themselves. This second system bothers me, as it makes me feel like feeding me is a chore.

Other interesting tendencies involve people who open their mouths as I take a bite and chew along with me, even though their mouths are empty. There's also the few talented, ambidextrous people who actually eat along with me by feeding me with one hand while feeding themselves with the other hand. It surprised me how comfortable I was with this rarely-used technique; it made me feel like less of an imposition and more like a friend. Somehow, the most annoying thing anyone has ever requested of me was to warn him before my last bite, almost as if he didn't want to waste his time picking up and putting down an unwanted mouthful of food.

Certain people stop feeding me when they get full, feed me things they like to eat, and

ignore the foods that they dislike. All of these traits happen to be true of my mother, something I realized only recently when we sat down for a meal where Mom fed me. I noticed soon after she filled my plate that it was identical to hers and was missing the sweet potatoes. Then I remembered that Mom does not like sweet potatoes. Nor does she like pickles, or soda, two things that I once thought that I didn't like either. At the same meal, Mom stopped feeding me all of a sudden and at first I didn't know why. It then occurred to me that Mom wasn't eating either and she probably thought that my stomach somehow filled up at exactly the same rate as hers did. I guess the umbilical cord has not been cut yet, as far as she's concerned. Reflecting back, this routine has been going on all my life and it's no wonder I didn't know how to answer when David asked me what I wanted to eat first.

In 1984 when I finally met my husband, Jim, who does not have a disability, I knew very little about him. On our first real date we met at a shopping center where they were having an accessibility expo, and he asked if I wanted to get something to eat. I remember going upstairs with him but ordering a large milk shake to drink while he had a salad and an assortment of things. He kept offering food to me, but I kept refusing, saying I wasn't very hungry. This time, I knew I was with a guy I liked, and I thought I didn't want to blow it by making him feed me!

Later on, I found out more about Jim and learned that he was already in a relationship where he fed his girlfriend. Cinda had MS, and as time wore on she had become more in need of help, so Jim was accustomed to feeding her. After we had a few dates where I had repeatedly told Jim I wasn't hungry, he came out and said, "Look, feeding you is really no problem." I replied, laughing, "Good, because I'm starved!" Everything was fine after that and today when I think about it I find it ironic. Not only was Jim feeding Cinda, but he had worked in many nursing homes and at that time was caring for his elderly father, who also needed some help eating.

Eating reemerged once again as a major issue during the years I worked as a Career and Independent Living Counselor at a college in New Jersey. John, my first boss, approached my feeding needs very informally; more often than not, he and I would eat together and he fed me as a matter of course. The other staff filled in, seemingly willingly, when John wasn't around.

One day I asked a fellow staff person to help me eat. She told me she was uncomfortable with having to feed me and she said she chose not to do it any more. I have to admit to being stunned. No one had ever reacted that way to me before, and at first I didn't know how to respond, nor what to do with my feelings.

In retrospect, I felt wounded, diseased and untouchable. I had been raised to believe that feeding me wasn't a big deal and my co-worker's remarks contradicted these age old beliefs. I had also thought we were friends, and I was not accustomed to my feeding needs being an issue among my friends. It also bothered me at the time that this person was working with people with disabilities and was still studying Special Education. Not wanting to feed me, in my mind, was a contradiction to her alleged convictions and it was a hard thing for me to swallow.

Not long afterwards, this same person became my supervisor and began a policy where I paid the office so that student aides working at lunch time would help me eat. This system usually worked out okay; but I almost always ended up being isolated and I never really felt comfortable around many fellow workers again! It was not long before some of the aides copped an attitude also and word drifted down that feeding me wasn't in their job description either! (Who ever put Cerebral Palsy in my job description?)

My next supervisor made eating actually more complex. Now student aides were no longer responsible to feed me; but, eating was a personal care need and thereafter, it was my own dilemma. I ended up hiring the campus nerd to assist me for two semesters and I chose to eat locked in my office. It is only now that I am beginning to put my own eating experience into some perspective.

I've noticed that I have never quite been the same about needing to be fed since my experience during my tenure working at the college. I still have feelings that feeding me is an imposition, but I suppose I am wiser for it!! Now I am much more cautious about whom I ask to feed me and realize that it is something that not everyone is comfortable doing!

Eating is something with which I continually wrestle. It remains my barricade from being

fully autonomous, and is a constant reminder of the enormity of my disability. I have never been out to a restaurant alone or even eaten any meal by myself. For that matter, I haven't ever been able to spend a day alone -- something everyone desires to do every once in a while.

In addition, refusing to eat is still a clear symptom of depression for me! Frequently when I go through a bad phase, the first thing I tend to do is avoid eating. After all, it is one area I still have some control over - I can decide when I eat and when I don't. It's easy to say I'm not hungry and make people believe me. At these times, I just eat when I absolutely have to have some nourishment. I guess I haven't changed my modus operandi much since leaving home and going to college.

Interesting, too, is my ineptness to select the food I eat, and especially planning the family meals. I am unsure still from where this inability comes but I can venture a guess! First, Mom chose my food early in my life, and I am not a picky eater! I also cannot cook and never had any interest in watching others in the kitchen; unless of course I could eat the batter! My inability to plan meals does deepen my negative feelings about myself as a mom and a spouse. However, choosing what to eat remains GREEK to me!!!

Currently, I get the most assistance from Jim when I eat. Crescent, Annie, and Jennifer feed me as part of their jobs as personal care assistants. I am comfortable with this arrangement most of the time. I cannot say I am entirely acceptable of having to pay for eating, or being fed, as I would like to be; but at least I've opened my eyes to the human reality.

I am just beginning to deal with the idea of Emily feeding me! I always strongly believed that it shouldn't be a responsibility for my daughter. I believed it just wasn't fair to expect this kind of help from someone to whom I had given life. However, I find myself rethinking this notion.

To begin with, Emily is occasionally showing interest in feeding me when she's in the mood. She first started by picking up finger food for me when she herself started to eat. Feeding me made her proud! More recently, when Jim was busy at the stove, she sat down and automatically fed me a complete meal! This was her idea completely her own initiative and went very smoothly. We were all very amazed! However, there are times when Emily is decisively against helping me. She is very uncomfortable with the fact that I drool. She calls my saliva 'slime' and it seems to truly disgust her. I cannot, and do not, blame her!

I must say my feelings about Emily 'having to feed' me changes periodically. On one hand, I would like her to live as normal a life as possible, but I must not forget that this IS her reality! Is it too much for her to feed me once in a while, especially if no one else is available? What lessons is she to learn if she is purposely kept from helping me? My disability-related needs ARE her reality and are something with which she has to deal. Besides, I do have to eat and it might be false to raise her to believe she has no responsibility at all to help me. I am walking a tight-rope when I try to figure what her role should be; and yet, I believe Emily will ultimately be the one who decides her own role.